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ABSTRACT

A retrospective review examined characteristics of 13 families involved in a community-based assessment and treatment program for children and youth with behavioral and emotional disturbance in association with mental retardation. Principles of stress theory and family systems theory are examined and applied to the particular stressors in families of children with disabilities. A chart for all 13 families lists child maladaptive behaviors and major family stressors and characteristics. Analysis suggests that in addition to the relevance of stress and family systems theory, the themes of parental loss and physical/sexual abuse are prevalent as major negative life events. The possible relationship of grief and grieving theory to aggressive noncompliance in conjunction with these theories is suggested. (Contains 14 references.) (DB)

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Characteristics of Families With a Child/Adolescent Who Has a Dual Diagnosis

A few years ago the Nisonger Center, UAP received a $300,000 grant from the National Institute of Mental Health to develop, implement, evaluate and disseminate a model curriculum for interdisciplinary pre-service professional training in community-based assessment and treatment of children and youth who have behavioral and emotional disturbance in association with mental retardation. The project had three major goals: a) to develop a curriculum representing appropriate state-of-the-art evaluation and treatment strategies; b) to foster an enduring basis for interdisciplinary collaboration among professionals who have the most service contact with this population in the community, including those who work in mental health, pediatric, and educational settings; c) to demonstrate how state-of-the-art evaluation and treatment services for children and youth with serious behavioral or emotional disorders and mental retardation can occur in generic mental health/health service agencies by designing the curriculum to be implemented in cooperation with representative generic field sites located in the community. During the time the clinic for children/adolescents with emotional disturbance and mental retardation was operating, the Social Work discipline was involved in the assessment of the families who presented a child for a behavioral assessment and intervention plan. A retrospective review of these families led to the development of this paper. There were fifteen families involved in the project. The following is a description and exploration of the commonalities and differences in thirteen of these families who have a child/adolescent with mental retardation and behavioral problems.

It is proposed that children and adolescents with dual diagnosis display emotional-behavioral problems in response to their psychosocial situations and

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relationships. There are recent studies with children who have normal intellectual functioning that show correlations between life-events and psychological problems. (Cowen et al., 1984; Sandler and Black, 1979; Hershel et al., 1973; and Hodges et al., 1984.) A literature review however was void for any studies on mentally retarded children's responses to major family life events. There are in fact no current studies which compare families who have a child with dual diagnosis and those families who have children with mental retardation without behavioral disturbance, yet, prevalence research indicates mentally retarded children have a 5-6 times higher rate of psychopathology than the child population at large (Matson and Frame, 1985). Gath and Gumley (1990) relate that 38% of children with Down's Syndrome, and 48% of children with a similar degree of retardation were judged to have "a significant behavior disorder which was severe and prolonged enough to cause additional handicap or suffering to the child and immediate family." Seltzer and Seltzer (1991) also point out that regardless of the severity of the mental retardation, behavior problems constitute the single most important variable influencing placement outside of the family and community settings. The rationale used in approaching this study is that of an interactive perspective, blending stress theory, and family systems theory. In order to assess the family of the dually diagnosed child from the perspective that it's stress experiences may be different from the family of a mentally retarded child who does not demonstrate emotional or behavioral problems, a multidimensional approach will expand the perspectives that concentrate only on genetic, biologic, and physiologic bases for disturbed behaviors in the cognitively-limited child.

A. **Stress Theory:** There are numerous approaches to identifying and defining stress. For this review, stress will be approached as the tension experienced when an event is perceived as harmful, threatening, or challenging to

feelings of well-being. It may be a positive or negative life change. It may be experienced cognitively, emotionally, or physically. Usually there is some combination of all three elements (Lazarus, 1966). From this perspective, stress is viewed as an initial perception of an event and not the result of failed coping. A situation may be managed adaptively, however the person is still reacting to stress. Understandably, there is greater concern regarding stress that is coped with ineffectively due to its negative impact on the mind and body. Stressors are those internal or external events that threaten, harm, or challenge personal feelings of well-being. Stressors may be related to: (1) critical life events, for example: divorce, illness, birth of a child; (2) "pile-up of daily hassles," for example: the multiple demands of child care, work, and family; (3) conflicts between two incompatible events or goals, for example: caring for a handicapped child when a sibling requires attention; (4) feelings such as disappointment, anticipation, uncertainty, and inadequacy. Whereas stress is a reaction, stressors are the actual events that elicit the reaction (Zeitlin, & Williamson, 1988; Johnson, 1986; Papalia et al., 1989). There is a considerable body of literature that deals with the assessment of life changes in adults that correlates with stress or stress-like events of adults, and the impact that they have both on adults' health and behaviors. The study of children and adolescents, modifying those studies on adult findings, is a relatively new area in stress and life events literature. Even more recently, focus has moved beyond adult or child/adolescent stress and has been transferred into the assessment of family stressors.

Over the years, many professionals have been interested in research on assessing life changes in relationship to outcomes of diminished health and social adjustment problems in adults. Many look to the works of Holmes and Rahe who have studied the impact of cumulative life changes; the works of Rahe and Lind,

1971; Lal et al., 1982; Kaplan et al., 1979; Bradley, 1979; and Hershfred et al., 1983, who have studied specific illnesses such as cardiac problems, diabetes, hypertension, pregnancy and birth complications, as well as work-related accidents, in relation to life events as stressors. The works of Dekhee and Webb, 1974; and Paykel, 1974; are examples of those who address the relationship of life changes to psychological adjustment-related variables such as depressive disorders, psychiatric symptomatology, and anxiety reactions. (Johnson, 23-29; Berlin, p. 600)

Recently, child life stress research has become an area of interest specifically for assessing stress that would influence mental health problems, prevention and early intervention approaches. Variations in measuring stress from a life events impact on nonretarded children and adolescents has been developed by Coddington (Life Events Record for Children, 1971) Johnson and McCutcheon's (the Life Events Checklist, 1980), Swearingen and Cohen (Junior High Life Experiences Survey, 1985), and the Adolescent Perceived Events Scales (by Compas et al., 1985). These scales primarily have been developed to assess and quantify the impact of life change in the child. Even though there is a need for additional studies regarding reliability and validity with these measures, the findings of research studies using these tools so far, indicate that negative change is correlated with problems of health and adjustment in children and adolescents with normal intelligence levels (Johnson, pp. 54-55; Berlin, p. 601). Little research to date is available on the impact of family life events as opposed to the impact of life events on the adults or a particular child or adolescent identified in the family. Most recently a scale of family-related stressors suitable for use with adolescents was developed by McCubbin et al., 1982, the Adolescent-Family Inventory of Life Events and Changes. (A-FILE) Another measure developed is the Family Inventory of Life Events and Changes (FILE) 1983, for use with other family members. These tools

have shown significant findings in the areas of stress and health status both with adolescents and families having a chronically ill child (Johnson, p. 53) These scales were developed out of a view that the family is a social system as suggested by Patterson and McCubbin (1983, p. 257) whereby "life events, those normative and situational, which are experienced by the family as a whole or by any one member are.added together to determine the magnitude of life change for a family. It is expected that cumulative family life changes will be associated with a decline in family functioning and with negative correlates in individual members."

B . Family Systems Theory: When the family is viewed as a balanced, social system ruled by unconscious or conscious rules about the roles of each member, the communication patterns, and other family processes, then symptomatology in one person, adult or child, can be seen as expressing a pathology that is located in the total system rather than in just one family member. Minuchin (1974) proposes that the family's essence is in its interactive nature: "...the individual influences his context and is influenced by it in constantly reoccurring sequences of interaction. The individual who lives within a family is a member of a social system to which he must adapt. His actions are governed by the characteristics of the systems and these characteristics include the effects of his own past actions. The individual responds to stresses in other parts of the system to which he adapts; and he may contribute significantly to stressing other members of the system. The individual can be approached as a subsystem or part of the system, but the whole must be taken into account" (p. 9). McGoldrick and Gerson (1985) agree with Minuchin as they assert that, "the physical, social, and emotional functioning of family members is profoundly interdependent with changes in one part of the system reverberating in other parts of the system. In addition, family

interactions and relationships tend to be highly reciprocal, patterned, and repetitive" (p. 5).

The interactive and interdependent characteristics of the family system comprise the foundations for the integration of the effects of life events and/or changes that result in stress. The identification of stress and its impact in the total system may be reflected in the child's behavior. The last decade has produced research in areas concerning intellectually normal children, stress, and mental health. Differences in children's adaptability to their family's stress are often explained by constitutional differences. Most children are resilient and able to adapt and cope with stress. Studies of children under stress suggest there are differences because of sex and constitution, the child's temperament, and the responses of others to the child and that these are significantly associated with psychiatric disorders (Rutter, 1983). Garmezy (1983) identified three factors that might protect children from the pathological consequences of stress: a positive disposition, a supportive family milieu, and an external social agency that strengthens and reinforces the child's coping efforts. Parental report is usually the source of child descriptions. These will reflect parental attitudes, values, and total family interactions. Severe and continued poverty and discrimination, often accompanied by family instability and inadequacy, have consistently been indicted as outstanding contributors to children's problems. These social risk factors place infants and very young children at physical and developmental risk. For older children, the destructiveness of these variables is augmented by difficulties in a larger community such as a dangerous neighborhood, poor schools, limited opportunities for enrichment and exploration, social and nutritional deprivation. Knitzer (1982) lists stressors in addition to poor and disorganized families: multiple handicaps; severe chronic physical illness; dramatic crises such as the death of a family member,

divorce, or parents with serious mental illness; and parents who are substance or child abusers (Encyclopedia of Social Work, 18th edition, 1987, pp. 111-121). According to Trad and Greenblatt (1990), the crucial factors in stress resistance and vulnerability are the status of the child's parental attachment and the milieu of origin, or family environment, Masten and Garmezy (1985) typically refer to stress resistance as the greater likelihood of successful adaptation despite exposure to stressful life events. Competence is defined as the ability to cope with life events/changes, relationships and task demands in ways appropriate to one's developmental stage. Some children do not have the protective factors available to them and often display aggression and other antisocial behaviors as a reaction to stress. Studies of conduct disorders immediately following acute stressful events are not available, but in almost all studies of individuals experiencing Post-Traumatic Stress Disorder (PTSD) caused by many different types of stressors, conduct disturbance is included as one of the panoply of post-stress symptomatology (Keith, 1990, p. 539) In an epidemological survey of young children, it was found by Richman (1977) that behavior disorders increase in direct proportion to the number of stressful life events. Life event research suggests that there is an increase in the frequency of stressful life events prior to the onset of conduct disturbance. Keith also indicates that it is well established that acute and chronic stresses in early childhood due to familial, parental, genetic developmental and socioeconomic disturbances result in increased risk (particularly in males) of chronic aggressive behavior and persistent conduct disturbances. It is also indicated that the younger the child the less solidified his or her character structure and hence the greater probability for aggressive acting out and conduct disturbance under stress. When confronted with stress, families also react in numerous ways in order to cope. Loss of family functioning and temporary disequilibrium can be a

family's reaction to a stressful (acute or chronic) (positive or negative) life change event. In order to maintain some level of stability it is known that family members can turn against each other, turn toward each other more, distance themselves from one another, become closer, or one member may develop symptoms. For families, as well as individuals, the nature of the experience and its compensatory adjustments depend on the meaning of the stress to them. Family members have a reciprocating network so what affects one member impinges on/and in turn affects every other member. Trad and Greenblatt cite studies that indicate that stress resistance can be related to social support which may come from extended family members or extra familial sources such as peers, trusted adults, teachers, school personnel, and from group memberships; however, they indicated that social support is of little help in protecting against or mitigating the effect of stress unless the individual uses that support (p. 40). Turkel and Eth (1990) support the position that stressors or negative life events can be correlated with symptoms in children and adolescents. A review of some of their studies show relationships between conduct problems and stressful life events as well as high correlations between parent's and child's responses to life events. They indicated that when the mother does not have social support or has poor trusting relationships in her own life, she is at greater risk for distress following stressful events. They concluded that in turn her child is at risk for emotional disorder. When the mother is well supported she can buffer stressful experiences and mitigate the influences in the child. Without the support for herself, the child is not shielded.

Much emphasis has been placed on how parents and families cope with life event experiences and resources (both internal and external), that are used as buffers to resulting stress. But what happens to the cognitively challenged child- what are the effects of the life changes, family life events on this child who has

	AGE	CHILD BEHAVIORS	FAMILY STRESSORS/CHARACTERISTICS
1)	8 years female	Aggressive to other children "Seizure-like" episodes Imitates other children's behaviors	Biological mother in treatment "nervous breakdown" Violent outbreaks Separated from both parents History of foster care Maternal great-grandmother caregiver Questionable sexual abuse history (attempted rape at 3 years of age by biological father) ADC check to biological mother
2)	14 years female	Tantrums Destructive temper Screaming episodes	Sexually abused at 10 years by friend of father History of foster care (present also)
3)	10 years male	Running away Biting others	Physical fighting observed between biological parents by children living with maternal grandparents Biological father alcoholic
4)	4 years male	Noncompliance Temper tantrums Self-injurious (head banging)	Physically abused by parents resulted in BI and services Adopted Abusive parents fear of discipline
5)	7 years female	Self-injurious behavior: • biting self • pulling hair out • pinching self • head banging	Lives in group home Father has custody Mother visits when child goes to father's Parental divorce Mother unstable?
6)	6 years male	Self abusive behavior Running away from home and school Screaming Aggressive	History of divorce Lives with natural mother Visits every other weekend with father Blended family : • step-father • his children • one child of their own
7)	8 years male	Withdrawal Self-talk Giggling Teases other children Excessive rubbing of genitals in public	Divorce Father has custody Mother did not visit for 3 1/2 years, now once a month Ongoing parental conflict
8)	12 years male	Noncompliance	Only child in intact family Father on medication for depression and OBD Parents are third cousins Paternal job stress Parental overinvestment
9)	13 years male	Running away Tore up school cafeteria Pulled knife on sister	Parental divorce Blended family (mother new marriage) Biological father – little contact (Michigan)
10)	14 years female	Tantrums Aggression	In foster family (FCCS) Separated 6 years ago from natural family Possible physical and sexual abuse
11)	9 years male	Noncompliance Communication ? (history hearing loss)	Maternal grandmother has been primary caretaker Now natural mother taking over as the maternal grandmother is dying ADC (never married) Overprotection patterns
12)	8 years male	Noncompliance (school) non-violent Touching children/teachers in inappropriate ways Pulling pants down in class	Intact marriage (8 years) Up until 3 months ago showered with mother Only child
13)	12 years female	Destructive; cruel to others (cats) Destroys property; irritable; impulsive; overactive; restless; mood swings; temper tantrums; threatens people; runs away; physically fights; grinds teeth	Adopted at 3 months Taken from parents for neglect, possible abuse Natural mother 15 years at birth Smoked/drank during pregnancy

learning differences, and what is done to help this child to deal with his or her feelings regarding the positive or negative stressors in relation to their families' experiences of changes or life events? The social/emotional development of many intellectually subnormal children is often ignored and neglected. The child who already has fewer resources (intellectually) for understanding, problem solving, and decision making, may be of much higher risk for behavioral disturbance. If so, then there is justification for this enquiry. Of the fifteen families interviewed in the EDMR Clinic, thirteen were assessed by Social Work. Family characteristics both in structure and process were identified. (See grid)

Please note on the grid the frequencies of the behaviors as correlated to the family's structure and experiences. It is evident that in addition to looking at stress and family systems theory, that the significance of the themes of parental loss and physical/sexual abuse are prevalent also as major negative life events. Further research is suggested to explore more in depth the relationship of aggressive noncompliance to grief and grieving theory in conjunction with Family Systems and Stress Theories.

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